




The Autism Spectrum Disorder

Advisory Consortium

Recommendations:
A Framework for the Future



Foreword

The Autism Spectrum Disorder Consortium was formed in March 2002 at the request of the State Interagency Council for Children's Mental Health. The Consortium was charged with providing a unified voice to assist SIAC in understanding the needs of children and youth with Autism Spectrum Disorders.

The Consortium is a 31-member body consisting of parents representing various support groups from across the state as well as representatives of parents who may not be associated with support groups. The Consortium also includes parents who have youth in transition to adulthood. The remainder of the Consortium consists of providers of services to children with ASD and their families, staff from the Kentucky Autism Training Center, a person with Asperger Syndrome and representatives from local and state level educational authorities. The ASD Consortium works in partnership with several identified consultants from state agencies, private non-profit agencies, evaluation centers and universities.

As the Consortium was forming, the 2002 General Assembly passed HB 455 which requires the Cabinet for Health Services to apply for a federal Medicaid waiver to address the needs of children and youth with ASD in Kentucky. The bill includes a three-month timeframe for the application. Despite the limited amount of time available for planning, The Department for Medicaid Services desired significant input from consumers, family members and providers and asked the Consortium to provide recommendations. In just four working days together as a full body the Consortium developed their initial framework for recommendations for the program and included those recommendations in this document.

“Recommendations: A Framework for the Future” is an initial attempt to aid the Consortium in their future endeavors and to provide primary information to Medicaid and the SIAC members. The document identifies numerous needs and concerns as well as initial recommendations, strategies and ideas to address the concerns. While sharing this preliminary document with SIAC, the Consortium asks that SIAC and her member agencies be aware that the ideas and recommendations included in the document are first steps and provide simply a framework based on the information available to the Consortium at the time. It is anticipated that the recommendations will evolve over time and will include more detail to aid the agencies in possible implementation.

Purpose of the Consortium

Prior to the formation of the Consortium, state agencies and policy makers were being besieged with massive amounts of differing types of information and ideas from various organizations, providers and families on the best approaches to serving children and youth with ASD. Many of the suggestions and ideas were conflicting in nature. These conflicts resulted in frustration, anger and eventually stagnation of progress for children with ASD. The ASD Consortium was formed to provide a unified voice by collectively utilizing the expansive expertise of the members. The Consortium serves as an expert advisory body on meeting the needs of the children and youth with ASD and their families in Kentucky.

Consortium Members

Jefferson Region

Kitty Wagner
6601 Windhurst Rd.
Louisville, KY 40207
502-896-2933
Fax: 502-899-5994
momcat76@aol.com
Jefferson County
Region 6J

Crystal Johnston
1302 Castlewood Dell
Louisville, KY 40204
502-495-7556
Fax: 502-459-3048
Crystalgj@aol.com
Jefferson County
Region 6J

Laurie Cottrell
8400 Hemp Bridge
Shelbyville, KY 40065
502-722-5633
Shelby County
Region 6S

Nathalie McKay
7607 Woodridge Dr.
Pewee Valley, KY 40056
502-241-7784
Nathmckay316@msn.com
Oldham County
Region 6S

Laurie Spezzano
5007 S. Hwy 53
Crestwood, KY 40014
502-222-4706
502-396-4928 cell
lauries@iglou.com
Oldham County
Region 6S

Laura Crawford
6805 Main St.
Westport, KY 40077
502-225-6292
laura@atticusproductions.com
Oldham County
Region 6J

Vicki Evans
Seven Counties Services
3717 Taylorsville Rd.
Louisville, KY 40220
502-459-5292
502-452-9079 fax
vevans@sevencounties.org
Jefferson County
Region 6J

Norma France
Family Links
7002 Oak Valley Dr.
Pewee Valley, KY 40056
502-643-1218
502-241-0774
njfrance@bellsouth.net
Jefferson County
Region 6J

Jeff Hadley
Home of the Innocence
1020 E. Market St.
Louisville, KY 40206
502-587-9260
jhadley@homeoftheinnocence.org
Jefferson County
Region 6J

John Burke
Kentucky Autism Training Center
571 South Floyd St.
Suite 100
Louisville, KY 40202
502-852-4631
JohnCBurke@Louisville.edu
Jefferson County
Region 6J

Rebecca Grau
Kentucky Autism Training Center
911 S. Brook St.
Louisville, KY 40203
502-852-7799
rebecca.grau@louisville.edu
Jefferson County
Region 6J

Eastern Kentucky Region

Lee Bowser
83 Little Acers Rd.
Lilly, KY 40740
606-864-4116
606-309-2067 cell
606-864-4576 office
leebowser@msn.com
Laurel County
Region 13

Rita Brockmeyer
100 Ross Dr.
Richmond, KY 40475
859-623-6074
859-623-9272 fax

Kay Marksberry
Powell County Board Annex
PO Box 180
Stanton, KY 40380
606-663-3330
Kmarksberr@Powell.k12.ky.us
Powell County
Region 15E

Trudy Abshire
PO Box 172
Louisa, KY 41230
606-673-4120
abby8@foothills.net
Lawrence County
Region 10

South Central Kentucky

Gayla Hayes
401 Peebles Ave.
Franklin, KY 42134
270-586-3367
Simpson County
Region 4

Dusty Phelps
Intrust Healthcare, UC
176 Enterprise Drive
Somerset, KY 42501
606-676-0638
dp_intrust@hotmail.com
Pulaski County
Region 14

Betty Dunning
571 Harrell Rd.
Franklin, KY 42134
270-622-6957
Simpson County
Region 4
Bettydunning@yahoo.com

Monica Bledsoe
Chestnut Park Child and Family Services
270-782-1116
270-782-9108 fax
270-646-0296
bmbledsoe@msn.com

Central Kentucky Region

Charla DeWitt
1012 Cliffwood Dr.
Bardstown, KY 4004
502-349-0214
chadew7275@aol.com
Nelson County
Region 5

Melanie Tyner-Wilson
243 Shady Lane
Lexington, KY 40503
859-278-4991
tynerwilso@aol.com
Fayette County
Region 15E

David Lane
1660 Woodlake Rd.
Stamping Ground, KY 40379
502-535-5919
dlane@lexmark.com
Scott County
Region 15W

Sarah Cordle
BIFAC
1099 South Broadway St.
Lexington, KY 40504
859-455-8430
mscordle@hotmail.com
Fayette County
Region 15E

John Roberts
DOSE
Hardin County Schools
110 South Main St.
Elizabethtown, KY 42701
270-769-8841
270-769-8885 fax
jrobert1@hardin.k12.ky.us
Hardin County
Region 5

Barb Kibler
Division of Exceptional Children, Ky. Dept. of
Education
500 Mero St.
8th floor, Room 806
Frankfort, KY 40601
502-564-4970
502-564-6721 fax
bkibler@kde.state.ky.us
Franklin County
Region 15W

Northern Kentucky

Sharon Reffitt
4016 Pointer Court
Florence KY, 41042
859-371-0043
sreffitt@fuse.net
Kenton County
Region 7

Dena Gassner
3233 Laurel Oak Court
Edgewood, KY 41017
859-341-8408
859-341-5069 fax
rgassner@fuse.net
Kenton County
Region 7

Western Kentucky

Sandra Sharpe
293 Toms Branch Rd.
Hartford, KY 42347
270-298-3635
SanLS1124@aol.com
Ohio County
Region 3

Patricia Williams
DOSE
Muhlenburg County Schools
PO Box 167
Greenville, KY 42345
270-338-2871
Muhlenburg County
Region 2

Vicki McLeod
DOSE
435 Berger Rd.
Paducah, KY 42003
270-538-4000
vmcleod@mccracken.k12.ky.us
McCracken County
Region 1

Rachel Butler
1629 S. Main Street
Apt. 147
Henderson, Kentucky 42420
270-314-1375 home
270-826-0416 fax
270-831-5142 work
rabutler@henderson.k12.ky.us
Henderson County
Region 2

How the Consortium was developed

In late February 2002, the State Interagency Council for Children's Mental Health (SIAC) requested the family leadership program within the Department for Mental Health and Mental Retardation Services to facilitate the formation and provide staffing to a Consortium of parents, providers and educators interested in issues pertaining to children and youth with ASD.

By March, an initial planning group was formed. Members of the planning group gathered information on all of the parent support groups across the state and contacted each one to ask for representation on the Consortium. Individual parent representatives were also contacted based on geographical and ethnic diversity. Leading providers of services for ASD and the Kentucky Autism Training Center were asked to designate representatives to serve on the Consortium. Finally, specific directors of special education were contacted based on recommendations from the parent groups. In order to be a member of the Consortium each person had to agree to attend an initial three-day retreat in Jabez Kentucky in April, 2002 and to abide by the operating guidelines for the Consortium.

Defining ASD

The first step for the Consortium was to clearly define the population of children and youth they were targeting. The Consortium adopted the definition used by the Autism Society of America.

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 2 to 6 in 1,000 individuals (Centers for Disease Control and Prevention 2001). Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

Autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

It is estimated that some 500,000 to 1,500,000 people in the U.S. today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism.

The ASD Umbrella

Several related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD—a general category of disorders which are characterized by severe and pervasive impairment in several areas of development (American Psychiatric Association 1994). A standard reference is the *Diagnostic and Statistical Manual (DSM)*, a diagnostic handbook now in its fourth edition. The *DSM-IV* lists criteria to be met for a specific diagnosis under the category of Pervasive Developmental Disorder. Diagnosis is made when a specified number of characteristics listed in the *DSM-IV* are present. Diagnostic evaluations are based on the presence of specific behaviors

indicated by observation and through parent consultation, and should be made by an experienced, highly trained team. Thus, when professionals or parents are referring to different types of autism, often they are distinguishing autism from one of the other pervasive developmental disorders.

Individuals who fall under the Pervasive Developmental Disorder category in the *DSM-IV* exhibit commonalities in communication and social deficits, but differ in terms of severity.

Autism:

Impairments in social interaction, communication, and imaginative play prior to age 3 years. Stereotyped behaviors, interests and activities.

Asperger's Syndrome:

Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.

Pervasive Developmental Disorder- Not Otherwise Specified (NOS):

Commonly referred to as atypical autism a diagnosis of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.

Rett's Disorder:

A progressive disorder which, to date, has occurred only in girls. Period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands replaced with repetitive hand movements beginning at the age of 1-4 years.

Childhood Disintegrative Disorder:

Characterized by normal development for at least the first 2 years, significant loss of previously acquired skills. (*American Psychiatric Association 1994*)

Autism is a *spectrum disorder*. In other words, the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit *any combination* of the behaviors in *any degree of severity*. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Commonalties of children and youth with ASD and their families

The Consortium acknowledges that every child and family is different and that their reactions and abilities to situations will vary. However, they also acknowledge that the children, youth and their families have a lot in common. The commonalties must be considered when addressing statewide needs of children and youth with ASD and their families.

Many families and caregivers of children and youth with ASD:

- Suffer from situational stress that affects marriages, siblings and extended family relations. The stress levels often result in increased physical illnesses of the family members and caregivers.
- Feel guilt and blame about their child's condition. According to the members of the consortium this is partially manifested due to the lack of an identified cause for ASD.
- Became aware of and reported difficulties when their children were between the ages of 0-18 months.
- Have developed low self-esteem as parents, which are linked to the limited emotional affirmation they may receive from their child and the lack of public awareness about ASD.
- Suffer from the social stigma associated with persons with disabilities and their families and caregivers.
- Experience financial stress due to the exorbitant costs of caring for a child/youth with ASD.
- Encounter grief, isolation and fear of the future.
- Believe that their personal value and societal judgment is based on their child's behavior.

Many children and youth with ASD:

- Have no physically distinguishing characteristics
- Exhibit repetitive behaviors
- Are often inflexible
- Exhibit various levels of verbal skills while some are non-verbal
- Have low muscle tone and postural control
- Demonstrate hyper or hypo states of sensory responsiveness
- Exhibit poor motor skills
- Exhibit deficits in social skills including many areas of pragmatics
- May present as having mental retardation
- Exhibit poor auditory and visual processing
- Demonstrate idiosyncratic methods of communicating such as pointing, using simple gestures or making a particular sound
- May exhibit compromised immune systems
- Often demonstrate food and environmental intolerance
- May develop severe behavioral issues such as tantrums, SIB and aggression
- Demonstrate unique attention difficulties such as only attending to a limited number of components in an instruction
- Display a deficit in imaginative play and peer interactions
- Demonstrate difficulties with abstract thinking

Identified service needs

Having agreed upon a definition for children and youth with ASD and considered the commonalties, the Consortium began reviewing the current service delivery system and identifying the most pressing service gaps and needs. The identified needs can be categorized into eight broad areas.

1. Funding

According to the Kentucky Department of Education December 1, 2001 child count of children with disabilities, there were 1,205 children identified as having autism. However, that count only represents the children with autism and does not reflect children with one of the other disorders under the spectrum such as developmental delay, multiple disabilities or those who are home schooled. Based on population and incidence rates it is estimated that there may be as many as 7,000 persons in Kentucky with ASD. The IMPACT Plus program in FY 02 served approximately 148 children with ASD. Given the disparity between the potential number of individuals to be served and the funding to be made available, it is difficult to see how a viable program can be made available that adequately addresses the needs of the individuals.

2. Training

There are very few providers in Kentucky currently providing services for children with ASD who have had more than a cursory workshop on autism. There are even fewer providers who understand the concept of ASD as a spectrum of disorders. Appropriate training to increase their knowledge is limited by the availability of funding. Furthermore, the Consortium recognizes a great need to establish a more intensive outreach training network for all urban and rural areas of Kentucky. While Kentucky does have an autism-training center, funding is limited which limits the number of teams that can receive training. The Consortium is most concerned that currently there are no requirements for providers to obtain specific training in order to provide services to children and youth with ASD by either Medicaid or private insurance companies.

3. Workforce development

An adequate workforce in human services is an issue for most persons with disabilities in Kentucky. However, the problem is magnified for children with ASD and their families since many of the behaviors common to children and youth with ASD are very unique. The behaviors are often compounded by the limited verbal or other communication deficits of the children as well as their

unique sensory and behavioral characteristics. Due to these limitations, those within the workforce must not only be willing to work with those who have disabilities and unusual behaviors but must also have specialized training to enable them to communicate with the child or youth.

4. Limited service array

The current service array for children and youth with ASD is inadequate. Research indicates that there are a variety of therapies that are helpful for this population of children. However, due to many factors such as training, the inadequate workforce, and the lack of a payor source, many of the services are simply not available. The Consortium noted that many of the services listed as available for this population are the traditional services provided for children with mental health disabilities such as outpatient therapy that are not conducive to children who are non-verbal.

5. Mandated model for service delivery

Many providers in Kentucky are aware of and are encouraged to utilize person centered planning and the wrap around model of support for children and youth with disabilities. However, the actualization of the model is proving to be very difficult. The Consortium states that many providers fall back to the traditional medical approach that denies parents and consumers the freedom to design an individualized program that is appropriate for the unique needs of the child and family. The providers point to arbitrary decisions and lack of understanding of payor sources for approval of individualized services. Many of the difficulties seen in the service delivery system may stem from not having a clear understanding of autism and the individualized issues seen in families.

6. Quality and monitoring

The current system of care, which includes medical, psychological and educational services for children with ASD has oversight in fiscal management but very limited oversight in actual clinical and functional outcomes, provider qualifications and individual outcomes for children. This lack of oversight and accountability perpetuates a cycle of poor services and even poorer outcomes without regard to cost.

7. Education

One consistent theme within the Consortium concerns the role of the Kentucky Department of Education in providing services for children with ASD. While some school districts are providing effective services within the limits of qualified providers, many are not. There is great concern among Consortium members that any program developed by Medicaid should enhance and not replace the LEAs in providing for the educational needs of these children. The Consortium is very aware of the limited funds available for this or any future programs for ASD and does not want to see local education authorities cost shift from IDEA to Medicaid. Further, the

Consortium clearly is concerned that the districts are not providing adequate services nor training to their providers and are not be held accountable.

8. Geographical Diversity

Kentucky children and youth with ASD and their families receive very different services based on the area where they live. Those in the Lexington and Louisville area have choices of different types of therapies and providers. Families who live in other areas of the state are limited to case management services from the local mental health center and must rely on all other services to be provided by the school district. Accessing evaluations for these children requires a several hour drive to Cincinnati or Louisville for most families.

A Vision for ASD in Kentucky

The Consortium concluded with what they already suspected the needs for these children, youth and families are great and the resources are limited. They immediately set to work to determine a vision, goals and tasks to improve the system of care for these children, youth and families.

Our Vision:

People with ASD in Kentucky will have a quality of life that ensures independence, self-sufficiency and happiness.

Goals:

- 1. Kentucky will have criterion based trained interventionists in every region of the state**

Objectives:

- Develop adequately informed and trained pro-active educators
- Develop an adequate workforce
- Participate in the Real Choices workforce development initiative
- Develop a parent/professional mentor program
- Create mandatory interdisciplinary training for **all** providers included in the ASD Waiver program
- Develop an emergency and four-year staff certification program for behavioral health professionals
- Develop certification program for staff supervision
- Train psychiatric hospitals and residential programs on ASD

- 2. Kentucky children and youth with ASD and their families will have access to effective interventions in the home, school and community that are:**

- Child-centered
- Multi-agency and collaborative in approach
- Inclusive of person-centered planning
- Based on the wrap around process
- Intensive, individualized and based on need
- Culturally and geographically diverse
- Year-round

Objectives:

- Develop and mandate a curriculum program that encompasses cultural awareness, parent/professional partnerships, person centered planning and individualized services for all providers of services for children and youth with ASD.
- Develop a plan to increase the current workforce
- Develop an incentive plan that will encourage more providers to become ASD certified.

3. Community awareness and understanding of ASD in Kentucky will increase while the associated blame and stigma will decrease**Objectives:**

- Develop a public awareness campaign
- Utilize support groups to provide training to community members on ASD
- Develop a public relations committee for the Consortium

Programmatic Framework Recommendations

Offering recommendations for an initial program for children and youth with ASD was by far the most difficult task the Consortium has had to date. Due to the fiscal restraints placed on the proposed program and the statewide budget deficit, the Consortium was faced with the dismal reality that the initial program could serve only a fraction of the children in need. This painful reality placed the Consortium in the unenviable position of making difficult choices on determining which children were most at risk and yet most likely to progress given limited treatment options. The process of developing the recommendations for the framework for the ASD program, served to strengthen the resolve of the Consortium to work with SIAC and its member agencies in creating cost effective, strength based services that will be accessible in every region of the state for all children with ASD and their families.

Given the fiscal restraints, the Consortium has developed a framework for a program for children and youth with ASD. It is estimated that there are approximately 7000 individuals in Kentucky with ASD and the initial program will only serve a portion of those. However, the Consortium is dedicated to working with agencies and legislatures to find alternative ways to serve these individuals and when appropriate to advocate for increased funding for this vulnerable population.

To determine which children should be served, the Consortium began by determining the highest child specific and environmental risk factors. Through a process of prioritization, the Consortium narrowed the factors down to the top seven for each category. The top seven **child specific** risk factors for children with ASD include:

1. Self-injurious behavior
2. Aggression
3. Being unaware of danger
4. Lack of appropriate communication skills
5. Co-morbidity
6. Lack of self-help skills
7. Abuse/neglect and victimization

The top seven **environmental** risk factors for children with ASD include:

1. Ineffective collaboration among systems that provide services
2. Insufficient funding
3. Lack of professionals trained in ASD
4. Lack of respite for caregivers and families
5. Lack of appropriate supports for transition from childhood to adulthood
6. Lack of training across systems and domains
7. Lack of entitlement to services

Eligibility

The Consortium compared their vision and goals to the risk factors and began to roughly categorize the children and youth with ASD in an effort to determine which children should be served in the initial phase of the ASD program.

The Consortium unanimously agreed upon the following premises and makes the following recommendations:

1. Children and youth should be eligible for the program regardless of the parent's income. However, a sliding fee scale called the "family wheel" should be implemented so that families share appropriately in covering the costs.
2. The program should serve only ages 3-21. Children under the age of three should access First Steps. The Consortium plans to address the needs of adults with ASD at a later date.
3. Children who are the most at risk for being institutionalized should have priority to services initially. However, the Consortium believes that early intervention is the key to long term success for any program for ASD. Therefore, the Consortium recommends a tiering or leveling approach to serving the children and youth with ASD. Based on this concept, the Consortium divided the targeted children into four categories.

GROUP ONE:

Children and youth with a primary diagnosis of ASD, who can not access other Medicaid eligible services for ASD, are currently placed out of the home or are at risk of immediate out of home placement due to:

Severe acting out behaviors that are self injurious, aggressive or dangerous to others and that have occurred over a four week period of time across one or more of the three life domains.

OR

Persistent moderate levels of acting out behaviors that are self injurious, aggressive or dangerous to others coexisting with severe deficiencies in sensory, social and communication development that occur on a daily basis over a four week period of time across one or more of the three life domains.

GROUP TWO

Children and youth who exhibit intermittent acting out behaviors that are self-injurious, aggressive, dangerous to others or coexisting with moderate sensory, social and communication deficits that occur on a daily basis over a three month period of time across one or more of the three life domains.

GROUP THREE

Children and youth who exhibit sporadic maladaptive behavior AND mild to moderate communication, social or sensory deficits for a six month period of time across one or more of the three life domains.

GROUP FOUR

All other children and youth with ASD in Kentucky.

Please note: The Consortium realizes that the definitions for each category are broad and need to be further defined. However, the recommendation is based on the CONCEPT of tiered or leveling the children in an appropriate manner.

Fiscal breakdown

The Consortium appointed a subcommittee to develop funding allocation options. To accomplish their charge the committee conducted a statewide school survey of directors of special education to determine the number of children with ASD currently identified by schools. The survey indicated approximately 12 percent of those children fall into group one, 25 percent in group two, 43 percent in group three and the remaining are in group four. The Consortium also considered several philosophical viewpoints that had been previously discussed by the Consortium members. Philosophies varied from providing very limited services to many children, to extensive service to a few children. The subcommittee also considered serving only the children in crisis from group one or only the children who may be the most likely to have positive outcomes from groups three and four. The subcommittee presented four options to the Consortium for their consideration:

Option A – serve Groups 1 and 2

- Group 1 = \$1.58 million @ \$12,000 individual cap
- (N=132)

PLUS

- Group 2 = \$313,000 spent on training only
- (N=313)

Option B – serve Group 1 only

- Group 1 ONLY, @ \$24,000 individual cap = \$1.872 million
- \$120,000 left for training
- (N=132)

Option C – serve Groups 1, 2 and 3 with shifting allocations

- Five percent of funding toward training
- 50 percent of the remaining 95 percent to Group One @ \$24,000 individual cap
- 30 percent of remaining 95 percent to Group Two @ \$15,000 individual caps
- 20 percent of remaining 95 percent to Group Three @ \$8,000 individual caps
- (N= 125) if every child actually capped. However, it would be expected that every child would not cap

- Each year the allocation for group one would decrease and the allocation for group three would increase

Option D: All groups/crisis split

- Ten percent toward systemic training.
- 45 percent of funds toward crisis intervention @ \$10,000 individual cap.
- 45 percent of funds toward non-crisis services @ \$3,000 individual cap
- (N=1205)

After carefully reviewing the options, the Consortium agreed that options A and B were not proactive and did not provide the best long term solution to meeting the needs of the children to be served in the program. They consider the approach narrow in thinking and strongly advise against any plan that serves only children in crisis. After much discussion and weighing the pros and cons of Options C and D, the Consortium finally agreed upon Option C as a unique plan they believe conceptually best utilizes the limited financial resources allocated to the program.

Option C allocates no less than five percent of the total appropriation for the program to implement a statewide system of training for parents, providers and educators. The training program, developed by the Consortium, would be required for any provider wishing to bill under the program but would also be available to others throughout the state. To supplement the training, the Consortium is recommending that families be required to pay a monthly fee based on a sliding scale. The sliding fees would augment the training budget. Finally, it is recommended that the providers also pay a small fee to supplement the cost of the training.

The remaining funds would be allocated for direct services to children, youth and families. Initially the largest amount of funding would be allocated toward the children identified in group one with limited funds allocated toward group two and group three. However, over a period of four years the allocation would decrease yearly for groups one and two and increase for group three. The concept behind this plan is to address the needs of the group one children and yet begin to emphasize the need for early intervention. Theoretically, the Consortium believes that if providers and parents are trained and intervention is provided early, then the number of group one children should decrease over the years. This concept allows for significant positive outcomes for more children.

Entry into the program

When determining how a child would enter a program, the Consortium reviewed past history of the current service array and at the fiscal realities of the future program. In an effort to ensure that every available dollar is directed toward the development or delivery of services for children, the Consortium strongly recommends that the regional interagency councils oversee the program.

The Consortium stated that the RIACs have a better understanding of the services available in the regions, have a better understanding of person centered planning and the wrap around model, have at least a minimum understanding of ASD, have experience in referral and nominations, can provide oversight to the program, can provide flexibility in implementing the program. The RIACs can also provide the oversight at no additional cost to the program. Many of the parents who have experience with the original model of IMPACT Plus and the RIACs believe that the approach was more appropriate provided fair decision making and had more expertise in handling issues of ASD.

While the Consortium feels strongly that the RIACs are the appropriate bodies for the ASD program, they strongly recommend at a minimal that Medicaid find an already existing mechanism to oversee the program without deducting administrative costs from the already dismal funds available.

The process for entry into the program would include the following:

- ✓ Child/youth has Axis I Diagnosis of ASD and has documentation from a QMHP to support the diagnosis
- ✓ Child/youth is between the ages of 3-21
- ✓ Parental consent for the referral
- ✓ Nomination packet is completed, and includes documentation proving child meets all of the entrance criteria and definitions for the identified population
- ✓ Nomination packet forwarded to the Local Resource Coordinator for the Regional Interagency Council
- ✓ Child is approved for services by the RIAC
- ✓ Child is served

Or

- ✓ Child is denied acceptance into the program and recommendations are made for other services

Needed Services

The Consortium reviewed the services currently available in Kentucky and in several other states and determined what they believe are those that are essential to children and youth with ASD and their families. The chart below lists the essential services, the general definition of the service, which group of children for whom the service should be available, if the service is available from other payor sources and finally if the service should be available under the program.

SERVICE	DEFINITION	GROUP to SERVE	FUNDING SOURCE	SHOULD THIS BE A PROGRAM SERVICE
Assisted Living 18-21	Facilitating the community integration of an individual in terms of vocation, recreation, independent living	All groups	Supported Living Grant, Supports for Community Living, Voc. Rehab.	YES Under TCS
Augmentative and Alternative Communication (AAC) and Assistive Technology (AT)	Screening, assessment, training, monitoring of effectiveness and equipment	All groups	LEA EPSDT Voc. Rehab.	NO
Behavior Management/ Therapy	Behavior management includes training, supervision, or assistance in appropriate expression of emotions, and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors.	All groups	Impact Plus but ends with waiver LEA within educational settings	YES
Case Management	An activity that assists a recipient in accessing needed medical, social, educational, training, and other support services in accordance with best practices in ASD.	All groups BUT OPTIONAL FOR GROUPS 3 AND 4	Community Mental health Centers	YES

Community Inclusion	An activity that assists a participant to acquire individually defined social and community skills and is delivered on a one to one basis or intimately small group.	All groups	LEA, Impact Plus but ends with waiver	Yes Under TCS
Crisis Stabilization	A 24/7 program up to 14 days, which specializes in ASD that is established to provide initial behavior management and medication stabilization services.	For group one only	Not for autism	NO But provide incentives
Day Treatment	A full day educational and therapeutic placement (classroom) program lasting a maximum of 12 months with intense follow-up services that is delivered on a regular education campus by specialized individuals highly trained in ASD with the goal of stabilization and return to their home school.	Groups 1 and 2	Not for ASD, is being provided for children with EBD	NO
Developmental Day Care	A part-time before or after school program to supplement an educational program by staff trained in autism and child development. This would include summering programming.	All groups	No	YES
Employment Supports and Development	The use of natural supports, job carving, job coaches, and person centered planning teams to facilitate the acquisition and maintenance of meaningful employment using a supported and competitive employment model.	All groups	Supported Living Grant, SCL waiver, LEA, Voc. Rehab.	YES UNDER TCS

Environmental Modifications	Physical adaptations to the home or vehicle, required by the individual's plan of care which are necessary to ensure the health, welfare and safety of the individual, or which will enable the individual to function with greater independence across three life domains.	All groups	Supported Living Grant Council for Retarded Citizens Center for Accessible for Living	NO
Individual and Family Counseling	Counseling for individual members or for the entire family to understand, cope, and be better prepared to meet the unique challenges associated with having a child with ASD in the family. In particular, in reference to receiving the diagnosis and addressing other life issues.	All groups	Medicaid, Impact, Impact Plus, LEAs to a degree, some university based centers, as well as public and private community organizations	YES
Parent to Parent Supports	Trained paid parents of children of ASD who will serve in a mentorship role to assist other parents to meet the challenges associated with having a child with autism in particular with accessing services, advocacy, and supporting the implementation of the children's plan.	All groups	No	YES
Occupational Therapy	Provision of evaluation and training services in the areas of gross and fine-motor functions, self-care and sensory and perceptual motor functions. Also may provide services directly or may demonstrate techniques to other service personnel or family members. Design, fabrication and adaptation of materials and equipment to individual needs across life domains. Trained in autism (sensory integration, sensory diet and strategies and techniques)	All groups	Often included in IEPs; however is inadequate to address the special needs of children with ASD	NO

Personal Care Services	Individualized ADL services for children whose parents or other caregivers are not able to meet the children's daily living needs.	All groups	CMHC	NO
Prevocational Services	Activities in assisting the individual with ASD in the preparation of gaining meaningful employment such as teaching such concepts as attendance, task-completion, problem solving, socialization skills, job readiness skills.	All groups	KDE, Voc. Rehab, CMHC	YES UNDER TCS
Psychiatric/ Psychological	Psychotropic medication management, standardized clinical assessments and recommendations	All groups	Medicaid LEA	NO
Residential Habilitation	Community-based, intensive residential placements for those individuals who cannot live at home at the present time because they require highly supervised and supportive environments.	All groups	Medicaid	NO
Physical Therapy	Treatment and training programs designed to preserve and improve abilities for independent functioning such as gross and fine motor skills, range of motion, strength, muscle tone, activities of daily living, mobility, through such means as purposeful activities, assistive and adaptive equipments, behavior adaptation and sensory stimulation	All groups	Medicaid	NO
Respite Care	Opportunity for families to meet personal needs while their child with ASD is cared for by a skilled professional.	All groups	Medicaid, Home and Community Based Waiver, Community Mental Health Centers and Supports for Community Living Waiver	YES

Skilled Nursing Services	Nursing services to conducted in the home for those individuals with ASD who have difficulty participating in services in traditional medical settings. (Physical, sensory and transition issues may inhibit access to health care services)	Groups 1 and 2	Medicaid	NO
Social Skills Training	Socializations-Supervision, or assistance in learning and practicing skills of cooperation and participation in order to benefits from being in the company of others. Services may include training supervision, or assistance in joining others in recreation, leisure or community activities.	All groups		YES UNDER TCS
Speech Therapy	Assessments, individual and group therapies based on the unique characteristics of autism: focusing on speech and language, pragmatics and social language, using of voice and/or augmented communication systems.	All groups	Often included in IEPs; however is inadequate to address the special needs of children with ASD	YES for initial consultation only. For the program: Assisting the team in setting up a system of communication. The program is not to be billed for on-going therapy.
Supplies and Equipment	Related equipment and supplies related to individual needs (non-medical)	All groups	EPDST, Medicaid	NO
Therapeutic Child Support	See Social Skills training, prevocational training, community inclusion, employment supports and development and assisted living. The definition would also include the current definition under IMPACT Plus for this service.	All groups		YES

Therapeutic Consultation and Training	Highly specialized, short term technical assistance to families and/or professionals in their implementation of intervention programs.	All groups	No	YES
Transportation	Service offered in order to enable individuals served on the waiver to gain access to community service, activities and resources, specified by the plan of care. This service is offered in addition to medical transportation and other transportation services. Whenever possible, family, neighbors, friends or community agencies, which can provide this services without charge will be utilized. Excluded are transportation costs otherwise payable as part of other services being utilized.	All groups	Supported employment, Medicaid	NO

Provider Qualifications

The Consortium believes very strongly that the keys to a successful program are strong provider qualifications and specific clinical and functional outcomes for both the child and program.

Below are initial recommendations for qualifications for providers under the ASD program. The Consortium recommends that EVERY provider under the ASD Program must undergo certification training for ASD. The training will be developed by the Consortium and implemented utilizing a portion of the overall program budget. The theory behind the required training is that by having appropriately trained staff early intervention may occur, the incidents of children in crisis will be reduced and cost will be contained.

In addition to core training in ASD, the Consortium recommends:

A. Augmentative Communication Devices/Assistive Technology –

- i. An Assistive technology specialists shall be approved by the cabinet based on the following qualifications:
- ii. Meeting minimum highest entry-level requirements for one (1) of the professions delineated in this administrative regulation or a rehabilitation engineer, licensed physician, nurse, OT, PT, ST, Audiologist, home health care and medical equipment supplier/retailer, hearing aid dealer, individuals or business known to be in the business of vehicle modification;
- iii. Having extensive knowledge, training, and experience in the field of Assistive technologies for individuals with disabilities; or
- iv. Meeting the qualifications in subparagraph 2 of this paragraph and be employed by an agency that provides Assistive technology services and be approved by the cabinet;

B. Behavior Management – Behavior Management providers must be:

- i. Level 1 Clinicians:
 - a) A licensed psychologist; board Certified Behavior Analyst; or master's level interventionist with a degree in behavioral science or social work with 5 years documented direct contact experience working specifically with the DD population inclusive of

experience: devising, implementing, and monitoring behavior support plans; supervision and training of others in the implementation of behavior plans; or

- ii. Level 2 Clinicians: (must be supervised by a Level 1 Clinician)
 - a) A master's level graduate with a degree in behavioral science or social work that does not meet the above qualifications; or
 - b) A bachelor's level clinician with professional equivalency and making reasonable progress toward a qualifying master's degree to be completed within two years; or
 - c) Certified Associate Behavior Analyst;
- iii. All behavior support plans and behavior guidelines require the review signature of a Level 1 Clinician. All clinicians providing behavior management supports are required to obtain a minimum of 10 CEU's annually or be enrolled in a qualifying master's or doctoral program. CEUs and graduate work must have courses which have a major focus on ASD.
- iv. Either a Level 1 or 2 clinician or individual must supervise individuals implementing behavioral services with professional equivalency.

C. Case Management –

- i. A provider of targeted case management shall be a person who is employed by:
 - a) The Department for Community Based Services (DCBS) as a case manager or social worker providing services to an individual in the custody of or under the supervision of DCBS;
 - b) A community mental health center as a provider of targeted case management services in accordance with 907 KAR 1:525; or

- c) A behavioral health organization and who shall meet the following requirements:
 - i. Have a bachelor of arts or sciences degree in a behavioral science from an accredited institution. A behavioral science shall include psychology, sociology, social work, human services, or special education;
 - ii. Have completed the equivalent of one (1) year of experience working directly with children. A master's degree in a behavioral science can substitute for the one (1) year of experience;
 - iii. Have completed a case management training program provided by the Department for Mental Health and Mental Retardation Services within six (6) months of the date of employment; and
 - iv. Receive weekly face-to-face supervision by a behavioral health professional, a behavioral health professional under clinical supervision, or a case manager who meets the requirements of this subparagraph and has two (2) years of case management experience.

D. Crisis Stabilization – To be provided by:

- i. A child-caring facility licensed in accordance with 922 KAR 1:305;
- ii. A hospital licensed in accordance with 902 KAR 20:009 and 902 KAR 20:016 or 902 KAR 20:170; or
- iii. A community mental health center;
- iv. Have a behavioral health professional with full-time clinical responsibility for the residential crisis stabilization program; and
- v. Have a behavioral health professional or a behavioral health professional under clinical supervision that shall have daily, face-to-face contact with the recipient. There shall be a behavioral health professional or a behavioral health professional under clinical supervision on site or on call at all times.

- E. Day Habilitation – should not require and on site MD but be licensed in accordance with 922 KAR 1:390 (Standards for residential child-caring facilities) and 902 KAR 20:078 (Operations and services of group homes).
- F. Developmental Day Care – licensed day care provider with ASD certificate training.
- G. Employment Support and Development – individual provider must be a part of the team and have supervision by a member of the team.
- H. Environmental Modifications – see assistive technology requirements but may include individuals qualified to install alarm system for home for safety or similar services.
- I. Parent to Parent Support – parent-to-parent support will be provided by a parent of an individual with ASD who:
 - i. Is employed by a behavioral health organization;
 - ii. Is approved by the Department for Mental Health and Mental Retardation Services following completion of ten (10) hours of initial and continuing annual training;
 - iii. Is directly supervised by a behavioral health professional or a behavioral health professional under clinical supervision;
 - iv. Receives weekly face-to-face supervision from a behavioral health professional or a behavioral health professional under clinical supervision; and
 - v. Provided by a person not related to or living with the recipient receiving the parent-to-parent support service.
- J. Personal care services – as per state regulations.
- K. Prevocational Services – transitional specialists as defined by the KDE or an individual in the community who must be a part of the team and have supervision by a professional member of the team.
- L. Residential Habilitation Services - Residential support services provided to an individual residing in an alternative living arrangement, which shall be a Group home, Staffed residence, or a Family home licensed in accordance with 922 KAR 1:390 (Standards for residential child-caring facilities) and 902 KAR 20:078 (Operations and services of group homes).

M. Respite Care – A respite provider shall:

- i. Meet all license, regulations, and other requirements applicable to the setting in which respite is provided;
- ii. Be approved by the individualized family service planning team. (23 Ky.R. 3142; Am. 3860; eff. 6-16-97; recodified from 908 KAR 2:150, 10-25-2001.)

N. Skilled Nursing Services – see state regulations for this service.

O. Supplies and Equipment – see assistive technology

P. Supported Living Services – as regulated by 908 KAR 2:190 (Supported living services) which includes

- i. A service providing agency; or
- ii. An individual who provides services, as employee or independent contractor.

Q. Therapeutic Consultation and Training – an individual meeting the minimum requirements as a professional of the discipline.

R. Transportation – see state regulations for this service.

S. Vehicle Adaptations – see environmental modifications.

T. In-home therapy – provided by a licensed or certified professional in the appropriate discipline.

U. Day Treatment – provided by:

- i. a behavioral health organization;
 - a) Under the supervision of a behavioral health professional or a behavioral health professional under clinical supervision;
 - b) Through a linkage agreement with the local education authority that specifies the responsibility of the authority and the provider for;
 - c) Appropriately-licensed teachers and provision for their professional development; and
 - d) Have a minimum recipient to staff ratio of four (4) children to one (1) staff. All therapy activities shall be led by a behavioral health professional or behavioral health professional under clinical supervision.

V. Therapeutic Child Support – (c) Provided by a person who is employed by a behavioral health organization and:

- i. Meets the following minimum qualifications for a professional providing a therapeutic support service:
 - a) Has a bachelor's degree from an accredited academic institution or be a registered nurse licensed in accordance with KRS 314.041.
 - b) Has one (1) year experience working with children who have behavioral health needs. A master's degree from an accredited academic institution shall substitute for the required experience.
 - c) Has sixty (60) hours of training in children's behavioral health or nine (9) college credits from an accredited academic institution in courses related to child development or services to children; and
 - d) Receives weekly face-to-face supervision by a behavioral health professional or a behavioral health professional under clinical supervision; or
- ii. Meets the following requirements for a paraprofessional providing a therapeutic support service.
 - a) Has a high school or general equivalency diploma and;
 - b) Has one (1) year of documented supervised experience working in a human service program **or** has six (6) months documented experience working with children in a supervised program setting if the therapeutic support service is provided one (1) on one (1) to a recipient outside a directly supervised setting or has one year of college credit and;
 - c) Receives weekly face-to-face supervision from a behavioral health professional or a behavioral health professional under clinical supervision.

W. Team Training –

Requires a Master's degree, advanced degree (MA or equivalent) in Special Education or related field and three years of experience in working with individuals with autism and other pervasive developmental disabilities. Providers must experience in developing and implementing community and school-based programs that address the unique behavioral, sensory and

learning styles of individuals with autism and other pervasive developmental disabilities. Providers must have documented experience delivering criterion-based training to parents, professionals and paraprofessional. Additional experience may be used on a one-to-one basis to offset the educational requirements.

X. Behavior Therapy –

- i. Behavior Therapist: see behavior management; and
- ii. Behavior Therapist Assistant: and individual with a bachelor's degree in field that has a minimum of 12 hours of pertinent coursework.

Y. Other Related Services

Certification and Training – This committee proposed the use of a criterion based training system that would include the following three levels:

A. Certificate Levels (levels of training):

1. Fundamental Understanding of Autism and intervention programs. This would be a standard training for all providers.
2. Discipline Specific training that includes didactic and practicum experience. This would be a discipline specific and diverse level of training that would be required for certain types of services (which still need to be specified).
3. Supervisor Training (training of trainers). Training would be a standard within each discipline for any individuals serving in a supervisory or training capacity.

The content of certificate level 2 trainings wouldn't necessarily change but delivery of the training would change (such as direct implementers being required to have hands on training).

Training Competencies

Preliminary Areas of Competency in Understanding The Major Characteristics Associated with Children and Youth with Autism Spectrum Disorders

(Specific areas for individual service team members will vary depending on role, children served, and desired outcomes. Additional Areas may be added to cover other topics and strategies).

Area 1: Autism Spectrum Disorders and Behavior	Area 2: Communication	Area 3: Social Skills	Area 4: Stereotyped And Repetitive Behaviors	Area 5: Sensory Characterist ics	Area 6: Neurobiological and Medical Aspects of Autism
History	Communication Development in Typically Developing Children	Social Development in Typically Developing Children	Stereotyped and Rep. Beh. in Children with ASD	Sensory Development in Typically Developing Children	Neurological aspects of child development.
Understanding ASD	Communication Development in ASD	Social Development in ASD	Conducting an Inventory of Stereotyped & Rep. Beh.	Sensory Issues in Young Children with ASD	Assessment tools in neurobiology.
Screening Methods	Conducting a Communication Inventory	Social Skills in Toddlers and Young Children with ASD	Determining the function of some stereotyped behavior	Sensory Issues in Youth with ASD	An overview of findings on the Neurobiology of children with ASD
Diagnosing Children with ASD	Augmentative and Alternative Communication In ASD	Social Skills in Youth with ASD		Sensory Issues in adults with ASD	Common Medications prescribed for children with ASD
Using a behavioral model for understanding autism	Social Language Use in ASD	Social Skills in Adults with ASD			Dietary Issues in the treatment of ASD
Collaborative Team Approach and the need to target generalization	Pragmatics in children, youth, and adults with ASD	Social Skills in the work place			Gastro-intestinal Issues

Proposed Competency Areas for Interventionists:

Major Strategies and Techniques Used with Children and Youth With Autism Spectrum Disorders

(Specific areas for individual service team members will vary depending on role, children served, and desired outcomes. Additional Areas may be added to cover other topics and strategies).

Area 1: Addressing Individualized Learning Styles & Behavioral Needs	Area 2: Communicat ion	Area 3: Social Skills	Area 4: Stereotyped And Repetitive Behaviors	Area 5: Sensory Characteristics	Area 6: Medical
An overview of Applied Behavior Analysis	Being Child Centered - Targeting Communication Intent/Scaffolding and Social Language Use in ASD	An overview of developing a social skills intervention program	An overview of approaches to target Stereotyped and Repetitive Behaviors	Understanding Sensory Development in Typically Developing Children	An overview of medical approaches commonly used with ASD
Fundamental Behavioral Teaching Principles & Procedures	Use of Direct Teaching (Behavioral) Methods	Direct teaching procedures	Teaching alternative behaviors	Sensory Issues in Young Children with ASD	The "DAN Protocol" and other dietary interventions diet
Prompting Strategies	Use of ABA strategies that involve naturalistic exchanges and components	Using peers and peer modeling	Using schedules visual supports	Sensory Issues in Youth with ASD	Addressing Sleep Issues
Natural Reinforcement & Preferred materials	Augmentative and Alternative Communication In ASD - Overview	Using natural teaching opportunities in targeting social skills	Using Video Self Modeling	Sensory Issues in adults with ASD	Addressing insistence on Sameness ("OCD") characteristics in ASD
Using Visual Supports to Increase Learning	Picture based communication systems and the use of American Sign Language	Using Social Stories			

Daily Schedules	Pragmatics in children, youth, and adults with ASD	Community and social skills using Peers and natural supports			
Incidental Teaching Procedures		Using natural supports in the work place			
Developmental Teaching Strategies - overview					
Ethical issues in using procedures to decelerate disruptive behaviors.					

Clinical and Functional Outcomes

Child Based Outcomes

Based on the identified risk behaviors, the following child based outcomes have been defined.

Self-injurious behavior

Intermediate Outcome- Child will reduce all severe or highly disruptive behaviors by 80 percent across the three domains as determined using systematic data collection procedures.

Outcome - Child will reduce his/her medically severe or highly disruptive self-injurious behavior to zero levels and these reductions will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

(Perceived) Aggression

Intermediate Outcome: Child would reduce all severe or highly disruptive behaviors by 80 percent across the three domains as determined using systematic data collection procedures.

Outcome - Child will reduce his/her behaviors that result in injury to others and/or damage to property to zero levels and these reductions will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

Unaware of danger

Outcome – When faced with dangerous situations that pose immediate harm to self, others, or property the child will demonstrate appropriate responses in these situations to avoid harm. These gains will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

Lack of appropriate/functional communication skills

Outcome - Child will use a functional appropriate communication system to communicate wants, needs, and emotions in a manner that would help reduce maladaptive behaviors and increase integration across the three life

domains. These gains will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

Severe deficiencies in sensory development

Outcome – The child’s sensory-based problematic behaviors are reduced to the degree that does not interfere with daily activities and inclusion across the three life domains and the reductions will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

Severe deficiencies in social development

Outcome – The child will demonstrate appropriate socially acceptable behaviors in previously problematic situations, as defined in part by the family, as well as in new situations across the three life domains. These gains will be maintained for at least six months or longer without direct professional intervention services provided under the proposed program.

Functional (social validation) outcomes

1. Programs will promote the progress necessary that will allow the child to remain in their home, community, and local integrated educational placement of parental choice.
2. Each child will generalize skills across the three life domains in order to live, interact and be educated with their typically developing peers.

Family Based Outcomes

- A. The family has been trained to implement and maintain an effective intervention program.
- B. The family members’ levels of stress in relation to the previously shown “risk factors” have been reduced to a level that they can maintain an effective intervention program.
- C. The family’s participation in community activities can occur on a more frequent basis with an improved quality.

Process Based Program Indicators

Below are the program areas that would be evaluated on a regular basis (these are not in order of importance):

- A. Level of proficiency of intervention team in implementing the program components. (The goal of these assessments would be to determine if further assistance is needed for the team to function more effectively.)
- B. Data Collection using objective measures along with social validation measures.
- C. Effectiveness of the behavior plan which was created using functional behavioral assessment, communication inventory, sensory profile, re-enforcer assessment, and adaptive behavior check-list.
- D. Evaluation of parent stress and family dynamics relating to having a child with autism.
- E. Periodic reviews of outcome data to determine if exit criteria have been met.
- F. Team consists of trained individuals across disciplines who are active members of the team.
- G. Efficient and effective communication, collaboration and cohesiveness among team members from across the three life domains.
- H. Regularly scheduled team meetings with consistent attendance of members with clearly defined agendas and specific delineation of roles and responsibilities. Meetings are scheduled at times convenient to all members on the team. Parents are active and equal members of the team.
- I. Child-based goals and objectives that are clear and complete and address the needs of the child and family that are based on a pre-assessment battery of child and family members.
- J. Program is well organized and each team has a program “book” which contains the collaborative service plan, data collection materials, graphs etc.
- K. Program supports families – How confident do parents feel in implementing program goals? Is there a process for parents to address concerns about service team or service plan?

Summary of Recommendations

- Increase the amount of funding
- Eliminate administrative costs from the program allocation
- Utilize a tiered/leveling approach to serving children
- Develop a statewide certification training program that is mandated for all providers in the ASD program and provide five percent of the total program allocation to fund the training
- Shift emphasis from crisis management to early intervention
- Develop mechanisms to ensure providers meet qualification and certification standards
- Develop an effective monitoring program based on clinical and functional outcomes
- Mandate person centered planning and wrap around models
- Ensure school involvement and prohibit cost shifting
- Increase the service array and ensure that it is geographically diverse
- Develop an adequate workforce

Future Plans and Concluding Statement

The Consortium will continue to meet in an advisory capacity to further refine their recommendations and to continue work with the SIAC. Training has been identified as a crucial issue for ASD and future endeavors for the Consortium will focus on developing recommendation for a systematic training plan. Long term goals also include addressing transitioning issues for youth and services for adults.

The members of the Consortium would like to thank the State Interagency Council for Children's' Mental Health and its' member agencies for the opportunity to provide recommendations on programs and services to the ASD population. Many complex issues challenge the families of children with ASD. They and their children have a variety of needs. The providers, schools and SIAC members have a vested interest in ensuring that those needs are met. For those reasons, it is essential that we continue to work together in collaborative partnerships. The development of the Consortium and the promise of enhanced partnerships have given hope to a better future to children and youth with ASD.